



94TH GENERAL ASSEMBLY

State of Illinois

2005 and 2006

HB4846

Introduced 1/19/2006, by Rep. James D. Brosnahan

SYNOPSIS AS INTRODUCED:

20 ILCS 2310/2310-354 new

Amends the Department of Public Health Powers and Duties Law of the Civil Administrative Code of Illinois. Creates a standing Task Force on Huntington's Disease within the Department of Public Health. Sets forth provisions for the composition of the Task Force and its operations. Provides that Members of the Task Force shall be reimbursed for their necessary expenses incurred in performing their duties and that the Department shall provide staff and technical assistance to the Task Force to the extent possible within annual appropriations for its ordinary and contingent expenses. Sets forth that Task Force duties include, (i) obtaining data and analyses regarding the prevalence and burden of Huntington's disease, (ii) coordinating the efforts of the Task Force with existing State committees and programs providing Huntington's disease education, counseling, and case management, (iii) raising public awareness on the nature of Huntington's disease, the value of early detection, options for testing, treatment costs, new technology, medical care reimbursement, and physician education, (iv) examining the limitations of existing laws, regulations, programs, and services with regard to coverage and awareness issues for Huntington's disease, and (v) receiving and considering reports and testimony from individuals and public and private health organizations to learn more about their contributions to Huntington's disease diagnosis and treatment and more about their ideas for improving Huntington's disease diagnosis and treatment in Illinois. Provides for annual reports to the Governor and General Assembly. Sets forth that the Task Force shall expire on April 1, 2009, or upon submission of the Task Force's final report to the Governor and the General Assembly, whichever occurs earlier. Effective October 1, 2006.

LRB094 17222 RSP 52511 b

FISCAL NOTE ACT
MAY APPLY

A BILL FOR

1 AN ACT concerning State government.

2 **Be it enacted by the People of the State of Illinois,**
3 **represented in the General Assembly:**

4 Section 5. The Department of Public Health Powers and
5 Duties Law of the Civil Administrative Code of Illinois is
6 amended by adding Section 2310-354 as follows:

7 (20 ILCS 2310/2310-354 new)

8 Sec. 2310-354. Huntington's Disease Task Force.

9 (a) A standing Task Force on Huntington's Disease is
10 established within the Illinois Department of Public Health.

11 (b) The Task Force shall have 10 members appointed by the
12 Director of Public Health as follows:

13 (1) A representative of an organization relating to
14 Huntington's disease.

15 (2) A representative of an organization providing
16 health care to patients stricken with Huntington's
17 disease.

18 (3) A health educator.

19 (4) A representative of a national organization
20 relating to Huntington's disease prevention who is a
21 neurologist.

22 (5) A representative of the health insurance industry.

23 (6) A representative of a national organization of
24 family physicians.

25 (7) The State Epidemiologist.

26 (8) A member at-large with an interest in neurological
27 diseases.

28 (9) A person specializing in research into
29 Huntington's disease.

30 (10) A licensed registered nurse.

31 The Directors of Public Health and Public Aid, and the
32 Secretary of Human Services, or their designees, shall be ex

1 officio members of the Task Force. The Director of Public
2 Health shall also consult with the Speaker of the House of
3 Representatives, the Minority Leader of the House of
4 Representatives, the President of the Senate, and the Minority
5 Leader of the Senate in the designation of members of the
6 Illinois General Assembly as ex-officio members.

7 Appointments to the Task Force should reflect the
8 composition of the Illinois population with regard to ethnic,
9 racial, age, and religious composition.

10 (c) The Director of Public Health shall appoint a Chair
11 from among the members of the Task Force. The Task Force shall
12 elect a Vice-Chair from its members. Initial appointments to
13 the Task Force shall be made not later than 60 days after the
14 effective date of this amendatory Act of the 94th General
15 Assembly. A majority of the Task Force shall constitute a
16 quorum for the transaction of its business. The Task Force
17 shall meet at least quarterly. The Task Force Chair may
18 establish sub-committees for the purpose of making special
19 studies; such sub-committees may include non-Task-Force
20 members as resource persons.

21 (d) Members of the Task Force shall be reimbursed for their
22 necessary expenses incurred in performing their duties. The
23 Department of Public Health shall provide staff and technical
24 assistance to the Task Force to the extent possible within
25 annual appropriations for its ordinary and contingent
26 expenses.

27 (e) The Task Force shall have the following duties:

28 (1) To obtain from the Department, if available, data
29 and analyses regarding the prevalence and burden of
30 Huntington's disease. The Task Force may conduct or arrange
31 for independent studies and analyses.

32 (2) To coordinate the efforts of the Task Force with
33 existing State committees and programs providing
34 Huntington's disease education, counseling, and case
35 management.

36 (3) To raise public awareness on the nature of

1 Huntington's disease, the value of early detection,
2 options for testing, treatment costs, new technology,
3 medical care reimbursement, and physician education.

4 (4) To examine the limitations of existing laws,
5 regulations, programs, and services with regard to
6 coverage and awareness issues for Huntington's disease.

7 (5) To receive and to consider reports and testimony
8 from individuals, local health departments,
9 community-based organizations, voluntary health
10 organizations, and other public and private organizations
11 statewide to learn more about their contributions to
12 Huntington's disease diagnosis and treatment and more
13 about their ideas for improving Huntington's disease
14 diagnosis and treatment in Illinois.

15 (f) The Task Force shall submit a report to the Governor
16 and the General Assembly by April 1, 2007 and by April 1 of
17 each year thereafter. The report shall include (i) information
18 regarding the progress being made in fulfilling the duties of
19 the Task Force and (ii) recommended strategies or actions to
20 reduce the occurrence of Huntington's disease and the burdens
21 from Huntington's disease suffered by citizens in this State.

22 (g) The Task Force shall expire on April 1, 2009, or upon
23 submission of the Task Force's final report to the Governor and
24 the General Assembly, whichever occurs earlier.

25 Section 99. Effective date. This Act takes effect October
26 1, 2006.